

MEETING MINUTES - <Survivorship Workgroup>

Date of Meeting: (09/15/2009)

Minutes Prepared By:
Pam Wilson

1. Purpose of Meeting

To go over Action Plan present updates

2. Attendance at Meeting

<i>Name</i>	<i>Department./Division</i>	<i>E-mail</i>
Linda Dziobek	Livestrong	ldziobek@yahoo.com
Gloria Hincapie	LLS	Gloria.Hincapie@LLS.org
Lauren Solomon	W&I	lauren_solomon4@yahoo.com
Tod Ellison	The MAE Foundation and VNA	MAE1171@aol.com
Jim Willsey	Roger Williams	jwillsey@rwmc.org
Judy Cerrito	YMCA	jcerrito@gpymca.org
Pam Wilson	RIDOH	Pamela.wilson@health.ri.gov

2. Meeting Agenda

AGENDA

1. Welcome
2. Minutes of August 18th Meeting
3. Survey Status
5. Action Planning
6. Other
 - Mini Workgroups Assigned
 - Survivorship Resource Fact Sheet – Arthur Plitt
7. Next Meeting – Tuesday, October 20th 4:00 pm

SAVE THE DATES

- Ovarian Cancer Walk, Sunday, September 27, 2009 Roger Williams Park
- Gloria Gemma, 5k Run/Walk and Flames of Hope, Saturday, October 10, 2009 Downtown Providence
- Making Strides Breast Cancer Walk, Sunday, October 25, 2009 Roger Williams Park

3. Meeting Notes, Decisions, Issues

1. The **Minutes** of August 18 Meeting were review and approved.
2. **Survey Status:** *See Action Plan status report below*
3. **Action Planning:** Linda explained that over the course of the summer Anna Wheat had met with the committee to finalize the action plan. The document presented at today's meeting is based on what group reviewed at last meeting with comments/edits made to it. Linda would like to get it to Anna for the CDC report. This is the working document. The data was updated. We left the deadlines. One reason we left deadlines in the report is to show that the survey is being held up with IRB review. With any Federal Grant, as long as you can provide the data why you can't meet the deadline, they understand. Linda went over the changes from last month's meeting. She noted that she gave the committee a week to comment on Action Plan. Arthur commented that we forgot to include an activity for complimentary care. *See Action Plan status report below for details.*
4. **Mini Workgroups Assigned** – Plan is to set up mini workgroups and then report at the main meeting. **Action: Pam is going to contact The Partnership to see if anyone is interested in joining a specific mini-workgroup.** Jim proposed that the 1st hour of Survivorship meeting, we will breakout into mini-workgroups and then last ½ hour workgroups will update the entire group. **Action: Pam will periodically email the groups to check on their progress and offer assistance and will cc: Linda & Jim.**
5. **Gloria Gemma "Flames of Hope" – October 10th.** **Action: Arthur offered to take a shift at manning The Partnership table. Pam will email Partnership for more volunteers.**

4. Action Items

Action	Assigned to	Status
<p>Objective A: Determine the needs of cancer survivors, gaps in care, and socio-demographic disparities within survivorship in the state of RI, by 2001</p> <p>Strategy 1: Conduct a cancer survivorship needs assessment survey</p> <p>Activity #1: Develop and conduct a statewide survivorship assessment survey</p>	Alvaro	Alvaro was not in attendance. Linda updated the group. The Treatment survey was approved last June. There was some understanding that DOH was not supporting the Survivorship Survey. That was a misunderstanding. The Survivorship group drafted a letter to Dr. Fulton. Alvaro provided additional information and the outcome was that Dr. Fulton said it would go through expedited review. Pam will find out status and review with Linda.
<p>Objective A: Determine the needs of cancer survivors, gaps in care, and socio-demographic disparities within survivorship in the state of RI, by 2001</p> <p>Strategy 1: Conduct a cancer survivorship needs assessment survey</p> <p>Activity #1: Carry out survey implementation and data analysis</p>	Linda/Alvaro	The mini workgroup will work to complete survey administration, collection, data analysis, and information dissemination.
<p>Objective B: Identify the currently existing resources for RI survivors by June 2010</p> <p>Strategy 1: Research all available resources for survivors in the state, including specific resources available disparate populations</p> <p>Activity 1: Create a one page "fact sheet" of compiled resources for survivors</p>	Arthur, Jim	Arthur did a 1 st draft of the sheet. Next meeting we will review it. Pam will invite members to join mini-workgroup.
<p>Objective C: Begin community education initiative addressing the needs of RI cancer survivors and the available resources by January 2009</p> <p>Strategy 1: Based on the results of the survivorship survey, educate patients, physicians, and/or care partners depending on gaps detected by survey results</p> <p>Activity #1: Launch an education campaign</p>	Lauren	Arthur suggested using the existing "Living Healthy Life with Chronic Conditions" education program. Maria.Mattias@health.ri.gov is the contact. Have funds to offer these classes to patients. The goal is to self-manage their disease and empower patients. Training done in RI at The American Association of Retired People.
<p>Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010</p> <p>Activity #1: Draft a RI Cancer Survivor's Bill of Rights</p>	Todd, Arthur, Judy	Jim suggested that the Bill of Rights be as detailed as the Patients Bill of Rights. Suggested we research if there is already an existing Cancer Survivor's Bill of Rights.

Action	Assigned to	Status
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #2: Create a statewide website with links to all available cancer survivorship resources	Gary, Lauren	N/A
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #3: Enhance resources available to survivors through the 211 United Way Helpline	Jim, Arthur	N/A
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #4: Assist with the planning of the annual State Cancer Summit	Jim, Brian, Linda D., Susan S., Pam, Bill K.	N/A
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #5: Support local and national cancer advocacy efforts as needed throughout the year	Linda, Jim	N/A
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #6: Work to bring socio-cultural diversity to the survivorship workgroup and the Partnership	Jim, Linda, Pam	Added this topic to the Executive Committee meeting on September 22 nd . Linda or Pam will report back to group.
Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010 Activity #7: Provide guidance to re-emerging Palliative Care Workgroup to promote the use of health living and evidence-based programs that address pain and the side effects of treatment	Leads TBD and Pam	<p>Arthur commented that we forgot to include an activity for complimentary care so Linda added this activity to the Action Plan.</p> <p>The subject of the Palliative Care workgroup was brought up by Pam. It wouldn't hurt to have them come to our meeting but Linda feels strongly that we are completely separate from Palliative Care. Lauren asked for a Definition of Palliative Care. Todd defined it: treats a person and not the disease. Looks at symptoms the person is having. To address quality of life. If they are in treatment, to help them to succeed in treatment. To provide the support they need according to each person. Pam will add Todd Ellison and Gloria Hincapie to be Palliative Care workgroup. Todd may chair or co-chair. He will follow-up with Pam.</p>

Action	Assigned to	Status
<p>Objective D: Develop an implementation strategy to develop and meet the needs of cancer survivors, by January 2010</p> <p>Activity #8: Promote the use of treatment planning/summary and cancer transition programs</p>	Leads TBD and Pam	<p>Linda added this activity to Action Plan. Judy Cerrito announced that Miriam Hospital has their own Cancer Transitions group. Linda discussed the Cancer Transitions program that was held at W&I. Part of that program was dedicated to medical management. Jim pointed out that National Cancer of Coalition Survivors is focused on treatment summaries. Workgroup should research who's doing cancer transition summaries and research accrediting bodies (ACOS, Community Cancer Centers of America). Focus is to bring awareness and educate patients to ask for treatment summary.</p>

5. Next Meeting

Date: (MM/DD/YYYY)	10/20/2009	Time:	5:30 – 7:00PM	Location:	RI Health Center Association
Agenda:	Activity Leads will update group on progress.				